

GENTOURINARY MEDICINE

Editorial

Resuscitation in HIV

The management of HIV infection requires a broad understanding of both medicine and ethics. This month's clinico-pathological conference¹ illustrates this in its discussion of repeated mechanical ventilation in a man of recent diagnosis, though advanced stage, of disease. In brief, a 49 year old bisexual male sought an HIV test after noting some weight loss and recent onset of poor memory. One month later he presented with rapidly progressive pneumonitis, and despite aggressive therapy (no specific opportunistic pathogen was isolated ante-mortem) he required two separate episodes of intubation and assisted ventilation. His first admission to the intensive care unit (ICU) was perhaps precipitated by a spontaneous pneumothorax; whilst the second arose from worsening parenchymal lung disease and sepsis from which he never recovered. This tragic but familiar story highlights the ethical conundrum "when should HIV care move from sustaining life to ensuring quality of death?"

The decision to resuscitate a patient can sometimes be straightforward: when faced with profound hypotension from massive cryptosporidial diarrhoea rehydration is an easy choice. However, this represents basic life support (that is the administration of fluid and nutrition); whereas the dilemma often lies within the domain of advanced life support—the use of inotropes, artificial ventilation and cardiopulmonary resuscitation (CPR). This review will deal mainly with the latter, using as a starting point, the history of the most frequent difficult decision—when to ventilate AIDS patients in respiratory failure. From this, we shall then discuss the interaction between the patient, their partners and family and their health care workers. Finally we propose some general guidelines to aid decision making in HIV disease.

In the early 1980s when AIDS was an unknown entity² if respiratory failure occurred secondary to severe disease, ventilation appeared to be a sensible and humane option. However, by the mid '80s it became apparent that the short term outcome in these patients was extremely poor with a mortality rate of 86–100%.³ Thus, whilst the absolute number of AIDS patients requiring ventilation rose there was in fact a decline in admissions to ICUs; and an acceptance by staff that a respiratory episode requiring ventilation was not compatible with survival.⁴ This was at variance with patient opinion at that time: Steinbrook's 1985 study of 118 San Francisco AIDS patients revealed that 55% would want ventilation, and 46% CPR in the event of life threatening *Pneumocystis carinii* pneumonia (PCP). (The patients did not distinguish between first, second or third episodes of PCP). However, patients

within the study estimated the survival after ventilation for first episode PCP as $53 \pm 23\%$ and for the second occurrence $30 \pm 23\%$; whereas at that time the reported survival rate was much lower (at best 14%).³ It was also clear that patients were keen to have a say in their own management; and make decisions regarding their future. As one patient in this study put it "I hope physicians everywhere will remember that they are dealing with real people and not with plastic dolls they can manipulate at whim. I am frightened, but not of death. Rather, I am frightened of being helpless".⁵

It was at about this time that AIDS activism was born. Groups such as "AIDS Coalition to Unleash Power" (ACT UP)⁶ were founded who were keen to influence HIV care. Wachter's 1987 study demonstrated the medical profession's response; as although 52% of AIDS inpatients were not for resuscitation, the decision had been taken jointly by patient and physician in 90% of these cases.⁷

In 1987 when zidovudine was shown to be of benefit in symptomatic HIV disease,⁸ the question of worthwhile survival post resuscitation arose once more. By now, there was also a suggestion of improved survival post ventilation for first episode PCP. El-Sadr and Simberkoff in New York⁹ had an ICU survival of eight of 19 patients (42%). However seven of the survivors were admitted to the ICU as a result of post bronchoscopy oxygen desaturation, whilst the systemic arterial oxygen tensions averaged 61 mm Hg in survivors compared to 45 mm Hg in non survivors. These two points have been interpreted by others as implying that the survivors were less ill, and in normal circumstances (if they had not been bronchoscoped) would never have required ventilation.¹⁰ However, El-Sadr and Simberkoff argued that because it was impossible to predict who would do well with mechanical ventilation, an aggressive approach to treatment was justified—and hence it was time to reappraise the minimalist view of ventilation in respiratory failure.

Further support for this came from Efferen and co-workers. In a review of 33 ventilated cases of PCP between December 1984 and June 1988, they showed 64% survival after the first episode and 25% for a second event. There was no difference between survivors and non-survivors in alveolar-arterial oxygen gradient on admission (taken as an indicator of hypoxaemia) nor in any other pre-admission clinical feature. The authors concluded that as they were not doing anything special in the way of patient management, it was their positive approach to ventilation that was responsible for improved survival data.¹¹

In the late 1980s reports of benefit from the adjunctive

use of corticosteroids began to appear in the literature for patients with moderate or severe PCP. When Wachter reviewed survival in comparable patients at San Francisco General's ICU between 1981–1985 and 1986–1988, there was an overall significant improved outcome (14% survival of 42 patients vs 40% of 30 patients respectively). Steroid usage was associated with 46% survival, and non-usage 22%.¹² The improved outlook led the authors to comment that as a result there was now “increased ICU utilisation by patients with AIDS, PCP and respiratory failure”.

Overall, patients with PCP are doing generally better (two year survival has risen from 2% to 17%)¹³ presumably owing to the sensible use of drug therapy (such as zidovudine, PCP prophylaxis, adjuvant steroids¹⁴ and “salvage” therapy¹⁵) and non-mechanical ventilatory support, for example Mask CPAP.¹⁶ It is also probably true that PCP is now picked up earlier in its disease course, owing to greater awareness of HIV related infection. Support for this comes from studies of outcome in PCP which have shown increasing duration of illness to correlate with reduced chance of survival. Other clinical indicators of severity include hypoxaemia or hypoalbumaemia on admission, and persistently elevated serum lactate dehydrogenase.¹⁷ Standard ICU outcome predictors such as APACHE II are unreliable.¹⁸ Recent work from Chicago by Peruzzi *et al* argued that the only predictors of mortality were acidosis at any time on ICU (ph < 7.35 and base deficit > 4 mmol/l); or the requirement for positive end expiratory pressure (PEEP) > 10 cm water after 96 hours of ICU care.¹⁹

The above review emphasises the changes that have occurred in the medical view of ventilation in AIDS. As “respect for an individual's autonomy” (a basic moral principle) requires that a patient receives adequate information before making a decision, it is clear that it is a doctor's ethical duty to give a patient the most up to date information.

For example, it has only recently been shown that if a patient with PCP survives ventilation then his outlook is just the same as someone with a less severe episode.²⁰ This however was not the stated view even two years ago.²¹

A doctor will often have a personal opinion of a patient's prognosis; however, it is important to remember that a key ethical principle in patient management is the determination of the true source of authority responsible for decisions of patient care.²² HIV disease illustrates this in several ways. As mentioned earlier, the AIDS lobby seeks medical autonomy, yet the very nature of HIV, its mode of transmission, and its association with gay sex, drug use and promiscuity mean that often patients are making decisions without a normal support network as they fear to tell others their diagnosis. This can be especially true in a family setting where, for example, the parents discover their young and apparently fit son on a ventilator with no previous knowledge of his diagnosis or even risk for HIV. Here the traditional pattern of authority and decision making breaks down as the family have no comprehension of the underlying disease let alone their son's wishes. The situation is even more complex when the son's partner (who may also be infected) chooses to be involved in the decision-making over and above the family's wishes.

The use of advance medical directives may avoid some of these problems. This relies on an individual, while still competent, to indicate preferences for or against medical intervention in the event of a loss of decision making capacity. This “living will” is not legally binding in the UK. However, from last December it was a requirement of hospitals and nursing homes in the USA to ask all admitted patients whether they had made advance directives; and if not to provide them with information about

this. (Patient Self-Determination Act 1990). Living Wills have not been without their critics, not least because of the complexity of covering all the potential scenarios in which they might be needed. However, their great advantage is that if properly used they can focus on individual values that might be relevant to a person's decision about life sustaining treatment. For example, they may clarify how a person views the balance between quality and quantity of life.²³

Another criticism of advance directives is that an individual may wish to change his decision at a later date. This may be because the medical information given to him has changed with time; that his physical state has altered or just that he has changed his mind. Work from Seattle where they interviewed ICU patients both during and after their admission is, however, reassuring, showing that (in a non HIV population) decisions made during serious illness appear to be constant and reliable (that is, what an individual would want when less ill).²⁴ This is important in a longterm fatal illness such as HIV. A final point regarding living wills is that in a study of an elderly population who had made advance directives, these were in fact only followed in 75% of cases.²⁵ And thus the will is only as good as those who enact it. Advance directives are now being used in HIV care in the USA; a recent American review of over 1000 patients showed that 68% of the sample know of their existence, whilst 28% had made formal prior directives. Thirty five percent of all patients had received counselling about this (11% from doctors) which increased the chance of making an advance directive three and a half fold.²⁶

The use of health care proxy directives (also known in the US as durable power of attorney) which designate a specific person as the surrogate decision maker in the event of a patient's mental incapacity, has also been advocated.²⁷ This has the advantage of being a formal acknowledgement of the way decisions are often made with the addition that the patient has the chance to state who should make such decisions. Hence in our example of the ventilated patient described earlier, it might be that he designated his partner to have medical power of attorney. This in itself would have encouraged the patient to state his own wishes to his partner at an earlier stage; and also, perhaps, acted as a catalyst to discuss his diagnosis with others such as his family.

The cost of HIV care is extremely high. With more life sustaining therapies (including intensive care) this becomes more expensive and also takes both money and beds from other specialities. Hence QALYs (quality adjusted life years where the additional life years associated with a procedure are combined with their quality) become an important issue.²⁸ If HIV care is to appear economically viable, it is imperative that we understand the limitations of our therapy. Peruzzi's study on outcome mentioned earlier¹⁹ is important as it offers guidelines on duration of care on an ICU. If we know that survival is reduced in PCP the longer a patient stays on ICU then we can set a specific date by which we hope to see an improvement. At this stage the situation can then be reviewed with friends and family enabling rational, compassionate yet economic decision making to take place.

Living wills are not legally binding in the UK, though in our unit we try to discuss advance directives with all our patients (in practice, this often means multiple interviews). We attempt to identify a next of kin, and to ascertain their own feelings and understanding early on in the disease. We are helped in this respect by a flexible HIV counselling service. Medically, we do not regard HIV positivity *per se* as a barrier to ICU admission (for example we would ventilate an HIV patient with an acute exacerbation of

asthma); and indeed reports from the USA show that 33% of ICU admissions are for reasons other than PCP induced respiratory failure, such as cardiovascular instability.²⁹ In general the prognosis of these patients is significantly better than that for severe opportunistic infection.

Our medical guidelines for resuscitation in AIDS patients are ventilation for either first time PCP (every episode we treat aggressively with steroids, CPAP and salvage therapy) or deterioration post bronchoscopy. If a patient is ventilated on ICU, we attempt to define a time by which we would expect an improvement (often seven days from starting treatment) and at this point review the situation with the patient's family/partner and other members of the medical and nursing team. We feel that CPR is not indicated in any situation where mechanical ventilation would be deemed inappropriate. In practice these guidelines appear to work well; though as implied throughout this text the final say in a decision should always remain with the real source of authority, whether that be the patient or their family.

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